Chapter 3 notes

Autism (Athabasca University)

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Chapter 3

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1. **Discuss the impact of autism on all members of a family.**
2. **Describe selection of interventions in home-based services.**
3. **Discuss the changing effects of ASD through the life span.**
4. **Discuss transition issues and their impact on the family.**
5. **Describe ways to support family members with a child with ASD.**

1- Discuss the impact of autism on all members of a family:

- Stress:
  - "Mothers of children with autism are one of the most stressed parental groups"
  - Children with autism who exhibit the most challenging behaviours create increased stress not only because of the difficulty in raising these children but also because of fear of public scrutiny, from both strangers as well as friends and families.
  - Behavioural challenges may limit a parent's ability to obtain social supports (known to relieve some of the stress)
- Depression:
  - Along with stress, depression is the most common associated negative impact of autism on families, greater for mothers than fathers
  - Fathers' stress and perceptions (positive or negative) were based on maternal depression; mothers' stress was dependent on their partner's depression, suggesting a cycle of interdependency and influence of psychosocial well-being among married parents or partners of children with autism
- Positive Impact:
  - A small fraction of the literature supports the idea that families, particularly parents and primary caregivers, experience positive effects of raising a child with autism.
  - Some parents say that raising an autistic child has a great impact on their lives, they feel like they are lucky and have been blessed with their child.
- Impact Over Time:
  - There is longitudinal research that suggests that the impact of autism on a family changes over time
  - Grey (2002) conducted a 10-year follow-up of parents of children with autism and found that initial concerns of parents, including high levels of emotional stress like depression and angel, were still present in the sample 10 years later but at much lower level.
  - Parents developed some coping methods, and it was mostly the parents of children with severe aggressive or obsessive behaviours that still experienced high levels of stress.
- Family Needs:
  - Financial support
  - Emotional support
  - Respite care (child care)
  - Resources to aid in understanding the child's disorder
  - Resources for dealing with the child's disorder
  - Teachers may wish to conduct a Family Needs Assessment to determine areas of need for the individual families with whom they work and prepare information sessions accordingly.

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- Another way to assist families with meeting their needs is to be empathetic to the fact that the families of students with autism have unique needs that may be very different from your own needs or those of other students with disabilities.

- Family Involvement:
  - For children with autism, family involvement is necessary for a number or reasons, including generalization of skills, parent support and training, collaboration across home and school, and ensuring that necessary skills are being addressed through the education plan.

2- Describe selection of interventions in home-based services:

- Early intervention:
  - The Individuals with Disabilities Education Act includes a provision providing for the development of an Individualized Family Service Plan (IFSP) for every child served under age 3 receiving services for a disability, which must be completed by a team of individuals including parents.
  - By law, parents must be a part of all decisions made relative to the education and treatment of their child with a disability.
  - It is up to early intervention (EI) personnel and parents themselves to determine the degree of participation parents will have beyond the minimum required by law.
- Special Education:
  - Families may be alarmed by the sudden lack of focus on their needs, having moved from an Individualized Family Service Plan to an Individualized Education Plan, which focuses solely on their child.
- Collaboration
  - Struggle for diagnosis
  - Fighting for Services
- Communication
- Trusting

3- Discuss the changing effects of ASD through the life span:

- Infancy and Early Childhood:
  - Upon initial diagnosis, parents and other family members may mourn the "loss" of the child they had hoped for.
  - They may come to terms and accept the disorder as part of their lives, it is important that professionals realize that depression, anger, and denial can recur at any time.
  - This is the time where families may be having more children, thereby creating some of the sibling issues and concerns.
- Elementary School Years:
  - Parents of children in elementary school may have decided on the treatments that they believe work best for their son or daughter and may be more relaxed in their pursuit of knowledge about the disorder.
  - The school years may be the time when a child with Asperger Syndrome is first diagnosed.
  - During these years, families may become more aware of the differences between their child and others without autism.
  - As children age, the gaps in their language and cognitive abilities become more pronounced.

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- Families may have concerns over a lack of friends and social opportunities for their child with ASD.
- Transition needs for the child and family at the end of the elementary school years include preparing student for differences in middle school and high school.
- Because children with autism often have difficulty with transition, professionals will need to work with the family to make sure proper supports are in place to make these daily transitions as smooth as possible.

- Adolescence:
  - For some parents, particularly children who are lower functioning, puberty may take them by surprise.
  - For females, the onset of menstruation is of greatest concern and hygiene skills become critical during this time.
  - These skills may take a while to teach because of the relative infrequency of opportunities to practice using feminine products.
  - For males, puberty brings a very different, but just as challenging, issue.
  - While higher-functioning children can be taught that masturbatory behaviours in public are not appropriate, the concept of appropriateness may be more difficult for lower-functioning students.
  - Until the lesson is learned, teachers must deal with the issue.
  - Increasing opportunities for independence should be a priority for adolescents with ASD, like getting their driver's license.
  - Transition becomes less about moving from class to class and more about deciding and planning for what children with autism will do once they leave the school environment at the age of 18-21.
- Adulthood:
  - As parents pass on, siblings begin to take on increased responsibility for their care; a task they may not be emotionally, psychologically, or financially ready to take on.
  - As teachers, we need to be aware of potential difficulties in adulthood and to be willing to discuss these difficulties with the entire family before the child with autism graduates or ages out of public schools.
  - Teachers should familiarize themselves with adult service agencies within their community that work specifically with individuals on the autism spectrum

4- Discuss transition issues and their impact on the family:

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5- Describe ways to support family members with a child of ASD:

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